Testimony Public Health Committee Proposed House Bill # 5525 An Act Concerning Cytomegalovirus Friday, February 20, 2015

To the Chairs, Senator Gerratana and Representative Ritter, distinguished vice-chairs, Senator Crisco and Representative Riley, ranking members, Senator Markley and Representative Srinivasan, and committee members:

I am Ann Blalock, a concerned citizen, and am in support of *H.B. 5525*: AN ACT CONCERNING CYTOMEGALOVIRUS.

My friend, Farah Armstrong, lost her second child, Madeline Leigh Armstrong, just over a year ago to the devastating effects of CMV, a virus she didn't even know existed before Maddie was born. Maddie was only twelve days old when she died. Since shortly after her death, it has been my great privilege to work with Farah and her mother, Becky Ghazi, in developing *Maddie's Mission* (www.maddiesmission.org), a grass-roots organization designed to promote congenital CMV awareness and prevention. We have learned much in this endeavor, most importantly that there is a critical need for policy mandating education for pregnant women and CMV screening for at risk newborns to minimize the incidence and severity of congenital CMV disease.

After Maddie was diagnosed, it only took a few minutes on the CDC website (www.cdc.gov/cmv) to learn that as the mother of a toddler enrolled in childcare, Farah was at high risk for contracting CMV during her pregnancy. The CDC Feature on CMV (www.cdc.gov/features/cytomegalovirus/) states that "toddlers often get CMV infections at preschool." Provided these children are otherwise healthy, they generally suffer no ill effects from the infection. They may have no symptoms at all, but they shed large amounts of virus in their saliva and urine for an extended period of time. When a child who is shedding CMV is part of a family, the infection rate for parents is about 20%. This is a 10 fold increase over the general adult population where the infection rate is about 2% per year! Had she known this from the beginning, Farah would also have learned that by careful practice of simple hygiene precautions designed to minimize contact with her child's urine and saliva, she could have greatly reduced her risk of contracting the virus while pregnant. Sadly, she did not know any of this in time to possibly make a difference for Maddie. While CMV counseling is recommended by both the CDC and the American College of Obstetrics and Gynecology (ACOG), fewer than 50% of obstetricians even mention CMV to their patients. These busy practitioners may not always have time to do what is recommended, but they will do what is mandated by law.

CMV was actually identified as a cause of neonatal disease as early as 1956 and still today only about 20% of women have even heard of it. One of the most devastating aspects of this for all CMV families (thousands each year across the U.S.) is that the prevention information is out there, but most parents only learn of it after they have an affected child. Many of these families might have avoided congenital CMV altogether had they been informed about CMV and the precautions available to minimize the risk of infection before their unborn children contracted CMV. While there is no pharmaceutical vaccine against CMV, studies have shown that pregnant women who are made aware of the risks and are educated about prevention measures can greatly reduce their incidence of infection. In this age of information, no one should be blindsided by congenital CMV!

While *Maddie's Mission* will continue to work to raise awareness and educate about prevention, the job is much bigger than we are.

Sincerely yours,
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